

AMCHP Annual Conference, 2010

Moving Ahead Together:

Celebrating the Legacy, Shaping the Future of Maternal and Child Health

The Nuts and Bolts of Building Community-Based Service Systems for CYSHCN

March 6-10, 2010

DIANE BEHL: And so on that intro I'm going to turn it over to Eileen to talk about what they did to assess communities.

EILEEN FORLENZA: So again having a sense of you know digging in at the trenches in the community this is the part where then you move into okay so what does the community look like? And so accessing the strategy of cultural brokers which is also another resource available on the National Center for Cultural Competence. Because I can tell you that as I moved into diverse communities I literally received feedback. Eileen I'm sorry but you are a white woman from the state and you live in the suburbs and you just cannot relate to our community. I love that honesty. I love that we are able to have that conversation. And so accessing the resources of the faith communities really looking at cultural brokers to help with those community tie-ins are very important. And I think that assessing the culture and the values of each community is a step in this step that's really important. In going to that level we had community focus groups basically. Now at this point these were not...later we had focus groups around our new messaging and our branding but these were focus groups with kind of community

leaders. And what can you do and how do you work on this? And that's when people are really willing to step in and say we'll take that piece. An example would be in transitioning youth with special health care needs out of pediatric system into the adult system. If you really look at it the education system, they're the ones that are supposed to do this, right? And for those of us who are parents and we know that we are building a transition plan in our kids IEP that's where in terms of the rubber hits the road. The department of education in your state is truly responsible. That doesn't mean that health doesn't get involved. But again as part of creating our niche and what do we really have impact to? Work with your local school districts. That is not necessarily only the role of Title V so pulling together, working with your school districts, finding your champion in those schools of who's connecting youth and transitioning in to those areas. And from there you'll find other community resources that will work. So that's an example of really pulling together a focus group at the community level and being honest about the options. And that, when we worked with the children's hospital for example, they said do you know what? If you guys would just consult with us on these few pieces, we'll take this part on. And same with the schools. We now have transition work groups in several, several communities across Colorado and they're of the community, for the community, by the community. Families have come together and working with their schools and a consultant from the health department on transition issues, so pulling together a focus group and having an honest conversation about what are the options, what can we do is the next step. And I know I'll say it again and again and again understanding that families are human capital at this time and that bringing in the right consumer voice at

the right level is a key part of moving into this third step of bringing your community together.

DIANE BEHL: Eileen, tell me a little bit more about how you presented options. What do you mean you presented options?

EILEEN FORLENZA: We talked about with our community partners we could keep doing this if this makes sense. Keep doing this meaning spending 80% of our budget on 20% of the population. We also knew that at the health department we were running into some HIPPA issues because as a state agency we had to finagle the HIPPA regs if we were going to continue to do direct services. Similar with our oral health; we could continue to pay for orthodontia care and that was going to again whittle down. Those were some of the options that we presented to our community partners. The community partners came back to us and said you guys really are the ones that connect everything. Our funding this is them talking, our funding tends to be so specific to diagnosis or you know like autism verse and education and the partners would come back and say but you guys really connect all of that and you guys have a connection with families so we'll continue to really dig in on the services if you guys will help us be connected. So we just put it out there about different options. We did say if you, the community really want us to continue to do this, do it the old way, we'll consider that. But they didn't do that.

DIANE BEHL: Thank you. All right. And so Harper's going to talk about some specific strategies that they use in terms of getting information from their communities.

HARPER RANDALL: So we needed to take our message off campus and into the communities and we developed surveys. One for families that were presently utilizing our clinics, how are we doing, what could we be doing better, are we meeting the needs and then another survey for the health providers that had kids going to our clinics. That allowed also to present ourselves and do a little bit of marketing and branding of who we were. And then we also had developed groups, focus groups, stakeholder groups within each community, not only to get information from them but also as a sort of an example of continued follow up. When we get those surveys back we're going to be sitting down and talking with you and did you know this is what your community looks like? So we will offer them something.

DIANE BEHL: Yeah, the one thing just to I guess emphasize with Utah again is the way they define their communities was looking at their traveling clinic sites that that was a good way to say if they're going to be the most impacted, let's start there. Okay now I've got the next one.

HARPER RANDALL: So again these were some of the questions that we looked at through these surveys. What are the availabilities of specialists and therapists that are within these communities that are again centered around our clinic sites? Are there other organizations in the communities that can assist in coordinating services, what type of family and youth leaders are currently active and are there other services that are inhibiting or supporting their efforts? Do we need to sort of get other people to the

table? Transportation, respite care, child care, public...increasing public awareness in the community...so these are a couple slides from our surveys and we had an overall summary of all of our clinic sites, but also we were able to break it down into each clinic area, each community. And so just in looking at this site these were...are these on the Y axis are these services available in your community? And if we're going to be...

DIANE BEHL: Am I...I think I am on the wrong slide, Harper, this one?

HARPER RANDALL: That one.

DIANE BEHL: Okay.

HARPER RANDALL: Are they available in your community? And do they see kids with special needs and do they take Medicaid. And so if we're going to try to fine tune our clinics and say every clinic should not be a cookie cutter pattern. We're going to offer certain services to one community because gosh, we didn't know it but now they have PT and OT and they can be members of the community coming to the clinic and staying in a community as opposed to packing up and leaving after the clinics over. So this slide again said gosh, if for a particular community we should really try to maintain neurology and genetics but maybe there's room to explore physical therapy audiology and have the community take over that. The next slide, we asked what are the family leaders and group advocacy efforts in your community. And what I found really interesting is about 20% of the providers said yep, we got...we have good strong advocates. Sadly, 26 said

no, there isn't anybody, but interestingly enough more than 50% said I had no idea. And that made me question do they understand how important it is to have them or have they not thought about it before? But certainly they didn't see that as...they weren't aware of it, they hadn't sought it out, they hadn't looked for it at very least. And then also with youth leaders, 10% said yes, we have a strong youth leader but almost 60% said no you know I don't know. Are there any youth leaders, I don't know? Again are they asking the questions, do they know how important that is? So the survey offered us a lot more information than we thought it might and we found it to be very helpful. And then we also developed a matrix. This is just a small part of it, but for each community we looked at the core pieces that are essential. And these again it's not the whole matrix but so we looked at for instance, family and youth leadership. Does it exist and to what level? What can we do to strengthen it? What do we need to do within the community...what should the community be doing to strengthen it? And so for each area we had both does it exist and then how can we help improve that?

DIANE BEHL: To save paper we didn't provide all these different tools in your packet, but they can be available by contacting us directly because you know it's a way to start and see if some of these would work for you. Okay Maine. Could you say that again, please?

UNKNOWN SPEAKER:

DIANE BEHL: Certainly, certainly. And it will be on the AMCHP as well along with the audio. But yes, we'd be happy to copy it. Toni, or Anna?

ANNA CYR: Anna. Actually our slide starts with community mapping in Aroostook County but I want to take a step backward and talk about how we began at the very beginning. We collaborated with our family to family health information center who have regional coordinators throughout the state of Maine. We met with them and asked them to set up focus groups in each of their regions. I'm sorry...catching your cold. Some of them were very well attended, some less well attended but whether they were well attended or not we got some very valuable input from each area. We also had already begun a family advisory committee and some of the people that we met in the focus groups became members of our family advisory committee.

HARPER RANDALL: See? They like that idea.

ANNA CYR: Was very helpful. Those groups were very helpful in letting us know what the issues were in their area. We discovered that Aroostook County had some...had a lot of issues, mostly based on their rurality so we have been working to set up a community mapping team in Aroostook County to get together with providers and other stakeholders in that area to get together and map out what the resources are. And by doing so identify the gaps and talk about how best to address those. And how to reach out to the rural families that are just way out in the boonie sticks. And so we've had a lot of good input from that group including a...what's it community relations development is

that who? From the one of the medical centers up there who is very interested in working with us on this so...is there anything else?

TONI WALL: I had just...this is the first opportunity I've seen Harper's little schematic there and I thought oh, I'm going to use that when we go up to Northern Aroostook County so it is a learning and sharing experience between all of us to say, wow, that's a great idea. We'll just take that with us and figure out how to use it up north so thank you.

UNKNOWN SPEAKER: Arizona also one of their grantees did community mapping in terms of assets that maybe out of the box or whatever if there was a granny who liked to knit and would make clothes for newborns at hospitals or if there was a rancher who had a couple of really nice horses or ponies and was willing to have children with special health care needs go and develop a relationship you know with a horse or a pony and get them to ride or whatever. I think out of the box kind of community assets that families may want that sometimes agencies don't really think about.

DIANE BEHL: example. Yeah, Anna, there's also on here how you're working with your family to family health information network?

ANNA CYR:I'm working actually through them and it's been very helpful in order to utilize their regional coordinators who are already out in the community who already have access to you know numbers of families and who know the issues. It was really important right off the bat to; I love this word, be transparent and tell them, this is what's

happening in this program. It's no longer going to look like what you're used to it looking like. This is what it's going to look like now. We need you, we need your involvement, we need your input, we want you to help us build this from the ground up and they were all over it. But I will also say that there was some distrust. There is some distrust amongst families saying yeah, yeah, I've heard it all before, it's always going to be the same as it is now. You know we are hearing that from people so that transparency and that trust building has to happen. It has to happen.

DIANE BEHL: Good point, Anna with the transparency and also that aspect that as you're assessing your communities look at those other key partners and they will give you an opportunity to say well we can help you get a handle of what's going on in your communities. Okay...should I skip this one or...Toni?

TONI WALL: I can just go over that really quick. These are what we're looking at at the community level really is the importance of medical home, the screening, resource and referrals. You know everybody has a resource and referral either in paper or in web-based and it's important to make sure that families are connected with those. Spreading the word about care coordination, developing partnerships with our community coalitions up in northern Maine and really developing youth and family leaders up in that part of the state. It's very rural up there. They feel separated from the rest of the state and they consider themselves the other part of Maine. And it is very different than the southern portion.

DIANE BEHL: Terrific. Champions Inc. has some tools available in terms of community mapping and other self assessment surveys that we've used in communities so again rather than giving you 50 pages of that we'd like you to follow up with us on getting those specific resources. I'm going to propose that we take just a ten minute break and when we come back I'd like to hear about some perhaps some acute community assessment strategies you're all using. Okay so I've got 10:45 Diana? Okay so let's be back here at five to 11, okay? Thanks.